REPORT TO THE TWENTY-THIRD LEGISLATURE STATE OF HAWAI'I 2005

PURSUANT TO SENATE CONCURRENT RESOLUTION 79
SENATE DRAFT 1 HOUSE DRAFT 1
REQUESTING THE HAWAI'I STATE COUNCIL ON DEVELOPMENTAL
DISABILITIES TO CONVENE A TASK FORCE TO IDENTIFY ISSUES
AND SOLUTIONS REGARDING INDIVIDUALS WITH
DEVELOPMENTAL DISABILITIES

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STATE OF HAWAI'I
DEPARTMENT OF HEALTH
STATE COUNCIL ON DEVELOPMENTAL DISABILITIES
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INTRODUCTION

In March 2003, The Arc in Hawaii closed several homes due to decertification of several of its Intermediate Care Facility for Individuals with Mental Retardation in the Community homes and the cost impact of maintaining those homes without Federal reimbursement. The closure of those homes resulted in urgency to place those affected individuals into residential settings appropriate to their needs.

In August 2003, the Department of Health, Developmental Disabilities Division and the Office of Health Care Assurance met with representatives from the Department of Human Services, Adult and Community Services Branch and Adult Protective Services to discuss the closure of Arc in Hawaii homes, recent adult protective services reports, and Centers for Medicaid and Medicare Services regulations for those individuals receiving services from the Home and Community-Based Services Waiver for individuals with developmental disabilities/mental retardation. The outcome of the meeting was that individuals receiving waiver services needed to reside in a licensed setting if they were not living in their own home or a home of a family member. This issue was brought to the attention of the Developmental Disabilities Division's Waiver Policy Advisory Committee because case managers from the Developmental Disabilities Division's Case Management and Information Services Branch were having difficulty finding residential alternatives for some of those individuals displaced from the closure of the Arc in Hawaii homes.

In November 2003, the Department of Health, Developmental Disabilities Division's Waiver Policy Advisory Committee recommended and the State Council on Developmental Disabilities (Council) Executive Committee directed the Council to convene a workgroup to identify issues relating to individuals living in a residential setting of their choice. As a result, in December 2003, Council staff initiated meetings and formulated a "Licensing Workgroup" involving Department of Health's Developmental Disabilities Division and Office of Health Care Assurance, self-advocates, family members and service providers to review current licensing requirements for adult residential care homes, adult foster homes and developmental disabilities domiciliary homes and to identify areas in existing statutes, administrative rules, policies, practices, and directives that conflict with the principles of self-determination, the Olmstead Directive and the integration mandate in Title II of the Americans with Disabilities Act. The Licensing Workgroup began to identify issues relating to an individual's choice of residential setting and has reviewed present statutes and regulations that govern adult residential care homes, adult foster homes, and developmental disabilities domiciliary homes.

Additionally, changes in recent Federal and State legislation and initiatives have influenced approaches for supporting individuals with developmental disabilities to live in the community. The United States Supreme Court decision in Olmstead v. L.C., 119 S. Ct. 2176 (1999) provided an important legal framework to enable individuals with disabilities to live in the most integrated setting appropriate to their needs. The Olmstead case was filed in 1995 by the Atlanta Legal Aid Society on behalf of two women, Lois Curtis and Elaine Wilson. Ms. Curtis and Ms. Wilson, who have mental retardation and psychiatric conditions, were living in a state psychiatric hospital. Treatment professionals determined that they were appropriate for discharge into the community; however, no slots were available to accommodate them. In June 1999, the United

States Supreme Court ruled that it is a violation of the Americans with Disabilities Act for discriminating against people with disabilities by providing services in institutions when individuals could be served more appropriately in community-based settings.

Chapter 333F, Hawai'i Revised Statutes, provides the statutory framework for the provision of services. According to Section 333F-7,

The department shall:

- (1) Assist the individual to develop, with the help of family and friends if necessary, an individualized service plan;
- (2) Identify the amount of dollars available to the individual to effectuate the individualized service plan; and
- (3) Allow consumers to direct the expenditure of the identified funds.¹

Olmstead and Chapter 333F provide the direction for individuals with developmental disabilities to live in the most integrated setting and for preventing inappropriate institutionalization. The focus is on promoting and engaging individuals with developmental disabilities to fully participate in their communities through self-direction. Individuals have choice and control over the services and supports they receive and have authority to direct their own budget. Emphasis is on individual choice and preference. Individuals live in the community with their families or with others in their own homes or in residential settings rather than in large state or privately-operated institutions.

The primary source of funding to support individuals with developmental disabilities to live in the community has been through the Title XIX Medicaid Home and Community-Based Services Waivers. Under the waiver, individuals with developmental disabilities may live with their families or in other licensed residential settings such as adult residential care homes, adult foster homes or developmental disabilities domiciliary homes. Current State regulations require homes to be licensed or certified to ensure health, safety and welfare of the individual.

Individuals with developmental disabilities in current residential settings may be required to move to another setting due to their change in condition, status of home and/or caregiver's license or certification, change in program requirements, etc. An individual with developmental disabilities should not be required to move and be displaced due to factors beyond their control, and if it is not their choice to do so.

Several individuals with developmental disabilities receiving services from Department of Health, Developmental Disabilities Division were removed from their current living arrangement that was not licensed, not because of their choosing, but because of the developmental disabilities domiciliary care home administrator's status of being denied a license from the Department of Health, Office of Health Care Assurance. There are other similar situations of individuals expressing to live in a setting that is not licensed; however, current rules and regulations do not allow this to happen.

¹ Chapter 333F, Section 333F-7, Hawai'i Revised Statutes, 2003 Cumulative Supplement

There is recognition that current rules and regulations can be more flexible to reflect individual choice and consider other factors, such as quality of life and overall well being (physical, emotional, psychological, social, etc.) of the individual.

The above issue has become an urgent one as:

- 1) Individuals with developmental disabilities exercise their right to make choices and direct their own budget and service plan;
- 2) Hawai'i implements the Olmstead Decision that individuals with disabilities live in the most integrated setting appropriate to their needs;
- 3) Hawai'i pursues increasing residential options for individuals with developmental disabilities;
- 4) Parents are no longer able to care for their son or daughter and seek residential placement; and
- 5) Sixty four percent of the individuals with developmental disabilities live at home and Hawai'i is eighth in the nation for growth in the over 64 year old population (see Table 1).

Hawai'i is challenged to increase residential options compounded with the high cost of living and lack of affordable housing. Some of Hawai'i's most vulnerable citizens are facing a crisis. In the past several years, Hawai'i has experienced unprecedented closure of facilities providing independent living options for adults with developmental disabilities. The losses of these residences have taken place across the State, on Big Island, Kaua'i, Mau'i, and O'ahu. The number of closures has continued to rise unchecked and have resulted in a housing crisis for this vulnerable population. While some new homes will be opened, more are on the verge of closing because operators cannot afford the loss associated with the low reimbursement attached to providing residential services to this population. Thus, the number of available residential options does not come close to meeting the current and future demand.

Decisions made in all crisis situations, especially regarding appropriate residential placement, have been based on the path of least resistance, specifically on what is the least harmful and available at any given time. The practice has often resulted in inappropriate, and to some extent, illegal placements which then need to be mitigated after the fact, and some times resulting in unanticipated cost to the State, for example, out of State placement.

In an effort to identify factors that created this crisis, make recommendations on how to stem the tide of this growing crisis, and identify immediate steps toward resolution of this crisis, the 2004 Legislature adopted Senate Concurrent Resolution 79 Senate Draft 1 House Draft 1 to address the issues and concerns regarding individuals with developmental disabilities having greater self-determination and choice in their place of residence.

The purpose of Senate Concurrent Resolution 79 Senate Draft 1 House Draft 1 was to request that the Hawai'i State Council on Developmental Disabilities convene a task force to identify issues and solutions regarding individuals with developmental disabilities and their choice of residential setting; and to submit its findings and recommendations, including any proposed legislation, to the Legislature no later than 20 days prior to the convening of the Regular Session of 2005.

The Task Force held its first meeting on May 27, 2004, and has since been meeting to address the activities of the resolution. Throughout the meetings, it became apparent that there are critical issues of residential settings for individuals with developmental disabilities that are complex and far reaching in scope.

This report is considered to be an initial report (Phase 1) describing residential options currently available for individuals with developmental disabilities, and statutes, administrative rules, policies, and directives that govern or impact on residential settings for those individuals. It is divided into ten sections beginning with recommendations of the Task Force.

The recommendations contained in this report are not inclusive of all recommendations considered and discussed by the Task Force. Due to the time constraints in completing the report 20 days before the convening of the Regular Session of 2005, the Task Force agreed by majority of its members to continue its work. This would include further review and analysis of statutes, administrative rules, policies, and directives. Furthermore, the Task Force would engage in continued discussion and outlining of the details of those recommendations that are not included in this report. A follow-up report (Phase 2) will be completed and submitted 20 days before the convening of the Regular Session of 2006.

I. RECOMMENDATIONS

Recommendations were formalized based on the review of statutes, administrative rules, current practices, and issues relating to residential options available for persons with developmental disabilities. The Task Force agreed to continue Senate Concurrent Resolution 79 Senate Draft 1 House Draft 1 to provide one more year for the completion of its duties to identify the issues and solutions regarding residential settings for individuals with developmental disabilities. The recommendations reflect the majority of the Task Force and may not be construed as having full support of all individual members.

1. Amend Chapter 321, Hawai'i Revised Statutes, Developmental Disabilities Domiciliary Homes

a. To amend Section 321-15.9 (f) to authorize the Department of Health to determine the rate of payment for residents in developmental disabilities domiciliary homes. The amendment would allow Department of Health to determine appropriate rate of payment that addresses individual needs and choice. Additional funds will be required from the Legislature.

The rate of payment would be in addition to the current State Supplemental payment of \$521.90 for individuals residing in domiciliary care.

The language to amend Section 321-15.9 (f) would be as follows:

"The rate of payment for residents in the developmental disabilities domiciliary homes shall be determined [on the same basis as domiciliary care homes as provided under section 346-53.] by the department of health."

Statutory material to be repealed is bracketed. New material underscored.

b. To amend Section 321-15.9 (c)(3): "Provide for plans of care which include community integration and [training] <u>support</u> of persons residing in the licensed homes." Statutory material to be repealed is bracketed. New material underscored.

The language for training individuals is outdated and was included in past contracts for providers of group homes. Focus on individualized service plans, plans of care, etc., is to support the individual to live in the community.

2. Amend Section 333F-2, Hawai'i Revised Statutes

Amend Section 333F-2, "(c)(9) Provision of community residential alternatives for persons with developmental disabilities or mental retardation, including group homes and homes meeting ICF/MR standards" by amending the above language to state, "Provision of community residential alternatives for persons with developmental disabilities or mental retardation, including [group homes and] homes meeting ICF/MR standards, and in a setting of his/her choice if the individual/circle of support determines that the individual can be sustained with supports, and the supports are attached to the person;"

Statutory material to be repealed is bracketed. New material underscored.

3. Department of Health, Developmental Disabilities Division, in collaboration with the Residential Settings Task Force, to revise applicable Hawai'i Revised Statutes and Hawai'i Administrative Rules regarding residential settings to reflect the principles of self-determination and individual choice.

This initiative will require at least one year to complete and could be accomplished during the interim period between the 2005 and 2006 legislative session.

4. Department of Health, Developmental Disabilities Division to pursue Supported Housing/Bridge Subsidy Program as a residential option through a pilot project.

The Department of Health, Adult Mental Health Division's Supported Housing/Bridge Subsidy Program has demonstrated success in allowing individuals with mental illness to live independently in housing of their choice. This model is a practical and realistic approach to increasing residential options for individuals with developmental disabilities. The pilot project would include a small number of individuals currently served by the Developmental Disabilities Division. The project would require funds in addition to Developmental Disabilities Division's existing budget from the Legislature.

5. Department of Health, Developmental Disabilities Division to establish a Housing Specialist within Developmental Disabilities Division.

A Housing Specialist shall have the responsibility to develop a comprehensive housing plan and implement the Supported Housing/Bridge Subsidy Program including coordinating with the Housing and Community Development Corporation, Housing and Urban Development, and other housing agencies to pursue other housing alternatives. This position would be located in the Developmental Disabilities Division. The authorization and appropriation for this position will be required by the Legislature.

6. Department of Health, Developmental Disabilities Division to initiate discussion with Ann O'Hara from Technical Assistance Collaborative, Inc., for information and technical assistance regarding housing options and projects.

Ms. O'Hara served as a consultant to the Department of Health, Adult Mental Health Division, in its implementation of the Supported Housing/Bridge Subsidy Program. She would be a great resource for Developmental Disabilities Division in providing technical assistance for the implementation of the Supportive Housing/Bridge Subsidy project and other housing options for individuals with developmental disabilities.

7. Department of Health, Developmental Disabilities Division to develop a comprehensive housing plan for individuals with developmental disabilities.

The plan should clearly identify specific action steps to address residential alternatives. Refer to Recommendation 5.

8. Department of Health, Developmental Disabilities Division to consider the following strategies in determining the rate of payment:

- a. Contracts for funding for agency-operated developmental disabilities domiciliary homes.
- b. A cost reimbursement and differential for shift staff.
- c. A higher rate to providers with a "no reject policy" for shift staff.
- d. Agency contracts that are based per program not based on the individual.
- e. Calculate for "vacant" days for individuals. This would be for unanticipated absences of the individual.

Note: Medicaid Home and Community-Based Services Waiver funds cannot be used to reimburse for vacant days.

9. Amend Chapter 89, Hawai'i Administrative Rules for Developmental Disabilities Domiciliary Homes.

Any amendments to Chapter 89, Hawai'i Administrative Rules will reflect amendments made to Chapter 321. Refer to Recommendation 1.

II. OUTLINE OF ACTIVITIES

Senate Concurrent Resolution 79 Senate Draft 1 House Draft 1 identified specific activities for the Task Force to implement. In identifying issues and solutions the Task Force was to:

- (1) Identify residential options available;
- (2) Address individual choice and self-determination in increasing residential options, including residency in unlicensed homes for individuals with developmental disabilities, such as adult residential care homes, adult foster homes, and developmental disabilities domiciliary care homes or those in the process of being licensed;
- (3) Identify statutes, administrative rules, policies, and directives to revise to allow homes that are unlicensed, but determined to provide safe and healthy environments, as a residential option;
- (4) Identify statutes, administrative rules, policies, and directives that need to be revised to reflect individual choice and assure civil rights, health, and safety; and
- (5) Coordinate its activities with the Olmstead Task Force to prevent duplication of work.

In addition to the above activities, the Task Force was to include representatives from the following agencies, organizations, or affiliations:

- (1) Individuals with developmental disabilities;
- (2) Family members of individuals with developmental disabilities;
- (3) Department of Health, Developmental Disabilities Division;
- (4) Department of Health, Office of Health Care Assurance;
- (5) Department of Health, Adult Mental Health Division;
- (6) Department of Health, State Council on Developmental Disabilities;
- (7) Department of Human Services, Social Services Division;
- (8) Hawai'i Disability Rights Center;
- (9) Office of the Public Guardian;
- (10) Residential services providers such as operators of adult residential care homes, developmental disabilities domiciliary care homes, and adult foster homes; and
- (11) Support services providers.

The Task Force was requested to submit its findings and recommendations, including any proposed legislation, to the Legislature no later than 20 days prior to the convening of the Regular Session of 2005.

Included in the resolution was that the Department of Health was requested to not take any action which would result in the relocation of any individuals with developmental disabilities without their consent from a home in which they reside merely because of the failure of the home to be licensed.

Certified copies of this Concurrent Resolution were transmitted to the Chair and Executive Administrator of the Hawai'i State Council on Developmental Disabilities, Director of Health, Director of Human Services, President of the Hawai'i Disability Rights Center, and Director of the Office of the Public Guardian. See Appendix A for Senate Concurrent Resolution 79 Senate Draft 1 House Draft 1.

The Task Force established guiding principles for addressing the licensing of homes and ground rules by which to operate and conduct its meetings. The following are principles for licensing of residential settings:

- 1. Always remember the golden rule, "Do onto others, as you would have them do onto you."
- 2. Every person with developmental disabilities must be seen and respected as a person first.
- 3. Persons with developmental disabilities have different needs, goals and dreams.
- 4. Persons with developmental disabilities must be given choices in their lives, with priority given to the least restrictive environment.
- 5. Persons with developmental disabilities have the right to be seen in our community.
- 6. Persons with developmental disabilities do contribute positively to our community.
- 7. Persons with developmental disabilities have the right to enjoy social activities independent of their caregivers.
- 8. All persons with developmental disabilities can communicate their needs and wants, given the appropriate supports.
- 9. Individuals with developmental disabilities have the right to have opportunities to pursue the same quality of life than those without disabilities. This includes civil and constitutional right to "life, liberty and the pursuit of happiness."

III. IDENTIFY RESIDENTIAL OPTIONS AVAILABLE

There are various residential options currently available to individuals with developmental disabilities. Of the 3,115 individuals receiving services from the Developmental Disabilities Division, the residential settings most used by individuals with developmental disabilities are as follows: 64 percent live with family, 19 percent live in Developmental Disabilities Domiciliary Homes or Adult Foster Homes, 8 percent live in Adult Residential Care Homes, 3 percent live independently.

A review was completed of residential settings available for individuals with developmental disabilities. The statutory and administrative requirements as applicable for each setting are described in Appendix C. It provides additional information on licensure/certification, funding, payment amount, number of units, capacity, pending applications, maximum number of individuals, current residents, persons eligible, services, and comments.

1. Adult Foster Homes

Statutory Provision: Chapter 321, Section 321-11.2, Hawai'i Revised Statutes

According to Section 321-11.2, Hawai'i Revised Statutes, 1993 Replacement,

- (a) The department of health is authorized to certify adult foster homes for developmentally disabled individuals requiring such care beyond the eighteenth birthday. "Adult foster home" means a private home providing care on a twenty-four hour basis for adults with developmental disabilities. To be certified, an adult foster home shall have not more than two adults with developmental disabilities at the same time, who are unrelated to the foster family. To accommodate residents of a foster boarding home for children with developmental disabilities who reach the age of eighteen years, where the home is certified as a foster boarding home for children under section 346-17, the director of health may waive the two adult limit for certification of that home as an adult foster home, provided that: (1) the number of foster children and adults in such dually certified home shall not exceed five, and (2) no new adults may be admitted into the home while there are any foster children residing in the home.
- (b) The rules of the department of human services adopted under authority of section 346-17, which prescribes the standards of conditions and competence of operation of child foster boarding homes shall apply to adult foster homes. Notwithstanding chapter 91, to the contrary, the rules shall be considered adopted by the department of health on July 1, 1986, for the purpose of regulating adult foster care homes and shall be valid until the department of health adopts rules pursuant to chapter 91. The department of health shall adopt rules pursuant to chapter 91 necessary for the purposes of this section.

(c) Rate of payment for adult foster homes is to be determined on the same basis as domiciliary care homes as provided under section 346-53.

Hawai'i Administrative Rules Title 11, Department of Health, Chapter 148, Adult Foster Homes

§11-148-2 Definitions

"Adult foster home means a private home providing care and training on a twenty-four hour basis for not more than two developmentally disabled adults who are unrelated to the foster family at any point in time."

§11-148-3 Need for certification

"An adult foster home shall have a certificate of approval in order to care for developmentally disabled adults."

§11-148-15 Number of individuals to be cared for

- (a) There shall be not more than two foster adults in an adult foster home. In the event the home is interested in providing day care for children and adults in addition to caring for foster adults, the total number of foster adults, foster children, and day care children and adults in the home simultaneously shall not exceed five. This requirement shall not prevent a home which provides care for foster adults from providing, in addition, day care for children and adults as long as this arrangement is not detrimental to the foster individuals under care and the hours of foster care and day care are not overlapping. The foster home, however, shall meet requirements under both rules governing foster family homes and family day care homes.
- (b) Not more than two foster adults and two foster children shall be cared for in a home by one foster family unless there is additional help approved by the agency. At no time shall there be more than four individuals under foster care.
- (c) A home which accepts agency placement shall not accept adults from any other source without permission from that agency.⁴

2. Adult Residential Care Homes

Statutory Provision: Chapter 321, Section 321-15.1, Hawai'i Revised Statutes

Adult residential care homes are defined in Section 321-15.1, Hawai'i Revised Statutes, 2003 Cumulative Supplement as,

² Title 11, Department of Health, Chapter 148, Section 11-148-2, Hawai'i Administrative Rules

³ Title 11, Department of Health, Chapter 148, Section 11-148-3, Hawai'i Administrative Rules

⁴ Title 11, Department of Health, Chapter 148, Section 11-148-4, Hawai'i Administrative Rules

Adult residential care home means any facility providing twenty-four hour living accommodations, for a fee, to adults unrelated to the family, who require at least minimal assistance in the activities of daily living, personal care services, protection, and health care services, but who do not need the professional health services provided in an intermediate, skilled nursing, or acute care facility.

A. Adult Residential Care Homes - Licensing

Statutory Provision: Chapter 321, Section 321-15.6, Hawai'i Revised Statutes

The Department of Health is responsible for the licensing of adult residential care homes. Section 321-15.6, Hawai'i Revised Statutes, 2003 Cumulative Supplement states,

- (a) All adult residential care homes shall be licensed to ensure the health, safety, and welfare of individuals placed therein. The department shall conduct unannounced visits, other then the inspection for relicensing, to every licensed adult residential care home and expanded adult residential care home on an annual basis and at such intervals as determined by the department to ensure the health, safety, and welfare of each resident. Unannounced visits may be conducted during or outside regular business hours. All inspections relating to follow-up visits, to confirm correction of deficiencies, or visits to investigate complaints or suspicion of abuse or neglect shall be conducted unannounced during or outside regular business hours or at intervals determined by the department. Annual inspections for relicensing shall be conducted with notice, unless otherwise determined by the department.
- (b) The director shall adopt rules regarding adult residential care homes in accordance with chapter 91 which shall be designed to:
- (1) Protect the health, safety, and civil rights of persons residing in facilities regulated;
- (2) Provide for the licensing of adult residential care homes; provided that the rules shall allow group living in two categories of adult residential care homes as licensed by the department of health:
 - (A) Type I allowing group living by five or fewer unrelated persons; and
 - (B) Type II allowing six or more persons including but not limited to the mentally ill, elders, the handicapped, the developmentally disabled, or totally disabled persons who are not related to the home operator or facility staff.

For purposes of this section:

"Mentally ill person" means a mentally ill person as defined under section 334-1.

"Elder" means an elder as defined under sections 201G-1 and 201G-151.

"Handicapped person" means an individual with a physical handicap as defined under section 515-2.

"Developmentally disabled person" means a person with developmental disabilities as defined under section 333f-1.

"Totally disabled person" means a person totally disabled as defined under section 235-1;

- (3) Comply with applicable federal laws and regulations of Title XVI of the Social Security Act, as amended; and
- (4) Provide penalties for the failure to comply with any rule.
- (c) The department may provide for the training of and consultations with operators and staff of any facility licensed under this section, in conjunction with any licensing thereof, and shall adopt rules to ensure that adult residential care home operators shall have the needed skills to provide proper care and supervision in a home environment as required under department rules.
- (d) The department shall establish a standard admission policy and procedure which shall require the provision of information that includes the appropriate medical and personal history of the patient as well as the level of care needed by the patient prior to the patient's referral and admission to any adult residential care home facility. The department shall develop appropriate forms and patient summaries for this purpose.
- (e) The department shall maintain an inventory of all facilities licensed under this section and shall maintain a current inventory of vacancies therein to facilitate the placement of individuals in such facilities.
- (f) The department shall develop and adopt a social model of health care to ensure the health, safety, and welfare of individuals placed in adult residential care homes. The social model of care shall provide for aging in place and be designed to protect the health, safety, civil rights, and rights of choice of the persons to reside in a nursing facility or in home or community-based care.
- (g) Any fines collected by the department for violations of this section shall be deposited in the general fund.

Hawai'i Administrative Rules Title 11, Department of Health, Chapter 100, Adult Residential Care Homes

§11-100-1 Purpose

"This chapter establishes minimum requirements for the licensure of adult residential care homes in order to protect the health, welfare, and safety of residents in adult residential care homes." 5

§11-100-2 Definitions

Adult residential care home (ARCH) means any facility providing twenty-four hour living accommodations, for a fee, to adults unrelated to the family, who require at least minimal assistance in the activities of daily living, but who do not need the services of an intermediate care facility. It does not include facilities operated by the federal government. There shall be two types of adult residential care homes:

⁵ Title 11, Department of Health, Chapter 100, Section 11-100-1, Hawai'i Administrative Rules

- (1) Type I home for five or less residents; and
- (2) Type II home for six or more residents.⁶

3. Expanded Adult Residential Care Homes

Statutory Provision: Chapter 321, Section 321-15.1, Hawai'i Revised Statutes

As defined under Section 321-15.1, Hawai'i Revised Statutes, 2003 Cumulative Supplement,

Expanded adult residential care home means any facility providing twenty-four-hour living accommodations, for a fee, to adults unrelated to the family, who require at least minimal assistance in the activities of daily living, personal care services, protection, and health care services, and who may need the professional health services provided in an intermediate or skilled nursing facility.

A. Adult Residential Care Homes Expanded Admissions

Statutory Provision: Chapter 321, Section 321-15.61, Hawai'i Revised Statutes

Section 321-15.61, Hawai'i Revised Statutes, 2003 Cumulative Supplement states,

- (a) Adult residential care homes may admit an individual who has been living immediately prior to admission in the individual's own home, a hospital, or other care setting, and who has been either:
 - (1) Admitted to a Medicaid waiver program and determined by the department of human services to require nursing facility level care to manage the individual's physical, mental, and social functions; or
 - (2) A private-paying individual certified by a physician or advanced practice registered nurse as needing a nursing facility level of care.
- (b) The department of health shall adopt rules in accordance with chapter 91 to expand admissions to adult residential care homes by level of care and to define and standardize these levels of care. The rules and standards shall provide for appropriate and adequate requirements for knowledge and training of adult residential care home operators and their employees.

B. Expanded Adult Residential Care Homes - Licensing

Statutory Provision: Chapter 321, Section 321-15.62, Hawai'i Revised Statutes

Licensing of Expanded Adult Residential Care Homes are governed by Section 321-15.62, Hawai'i Revised Statutes, 2003 Cumulative Supplement as,

⁶ Title 11, Department of Health, Chapter 100, Section 11-100-2, Hawai'i Administrative Rules

- (a) All expanded adult residential care homes shall be licensed to ensure the health, safety, and welfare of the individuals placed therein.
- (b) The director shall adopt rules regarding expanded adult residential care homes in accordance with chapter 91 which shall implement a social model of health care designed to:
- (1) Protect the health, safety, civil rights, and rights of choice of the persons to reside in a nursing facility or in home- or community-based care;
- (2) Provide for the licensing of expanded adult residential care homes for persons who are certified by the department of human services, a physician, advanced practice registered nurse, or registered nurse case manager as requiring skilled nursing facility level or intermediate care facility level of care who have no financial relationship with the home care operator or facility staff; provided that the rules shall allow group living in two categories of expanded adult residential care homes as licensed by the department of health:
 - (A) Type I home shall consist of five or less residents with no more than two nursing facility level residents; provided that more nursing facility level residents may be allowed at the discretion of the department; and
 - (B) Type II home shall consist of six or more residents, with no more than twenty per cent of the home's licensed capacity as nursing facility level residents; provided that more nursing facility level residents may be allowed at the discretion of the department; provided further that the department shall exercise its discretion for a resident presently residing in a Type I or Type II home, to allow the resident to remain as an additional nursing facility level resident based upon the best interests of the resident. The best interests of the resident shall be determined by the department after consultation with the resident, the resident's family, primary physician, case manager, primary caregiver, and home operator;
- (3) Comply with applicable federal laws and regulations of Title XVI of the Social Security Act, as amended; and
- (4) Provide penalties for the failure to comply with any rule.
- (c) The department may provide for the training of and consultations with operators and staff of any facility licensed under this section, in conjunction with any licensing thereof, and shall adopt rules to ensure that expanded adult residential care home operators shall have the needed skills to provide proper care and supervision in a home environment as required under department rules.
- (d) The department shall establish a standard admission policy and procedure which shall require the provision of information that includes the appropriate medical and personal history of the patient as well as the level of care needed by the patient prior to the patient's referral and admission to any

expanded adult residential care home facility. The department shall develop appropriate forms and patient summaries for this purpose.

(e) The department shall maintain an inventory of all facilities licensed under this section and shall maintain a current inventory of vacancies therein to facilitate the placement of individuals in such facilities.

4. Assisted Living

Statutory Provision: Chapter 321, Section 321.1, Hawai'i Revised Statutes

As defined under Section 321-15.1, Hawai'i Revised Statutes, 2003 Cumulative Supplement, "assisted living facility means a combination of housing, health care services, and personalized supportive services designed to respond to individual needs, to promote choice, responsibility, independence, privacy, dignity, and individuality."

Hawai'i Administrative Rules Title 11, Department of Health, Chapter 90, Assisted Living Facility

Chapter 90 established a new category of community-based residential care setting "to protect the health, welfare and safety of residents" in assisted living facilities. "Assisted living facilities shall serve the purpose of providing a combination of housing, meal services, health care services, and personalized supportive services designed to respond to individual needs." "The following principles are applied:

- (1) Aging in place;
- (2) Negotiated plan of care; and
- (3) Managed risk."⁷

§11-90-2 Definitions

Assisted living facilities means an assisted living facility as defined in section 321-15.1, HRS. This facility shall consist of a building complex offering dwelling units to individuals and services to allow residents to maintain an independent living lifestyle. The environment of an Assisted Living Facility shall include one in which meals are provided, staff are available on a 24-hour basis and services are based on the individual needs of each resident. Each resident, family member, and significant other shall work together with facility staff to assess what is needed to support the resident so that the resident can achieve his or her greatest capacity for living independently. The facility shall be designed to maximize the independence and self-esteem of limited-mobility persons who feel that they are no longer able to live on their own.⁸

⁷ Title 11, Department of Health, Chapter 90, Section 11-90-1, Hawai'i Administrative Rules

⁸ Title 11, Department of Health, Chapter 90, Section 11-90-2, Hawai'i Administrative Rules

"Activities of Daily Living or ADL means those personal functional activities required by an individual for continued well-being including eating, dressing, personal hygiene, mobility, toileting and behavior management."

"Assisted living means encouraging and supporting individuals to live independently and receive services and assistance to maintain independence. All individuals have a right to live independently with respect for their privacy and dignity, and to live in a setting free from restraints."

"Independence means supporting resident capabilities and facilitating use of their abilities. Independence is supported by creating barrier free structures and care design of assistive devices." 9

"Independent means the resident can perform the ADL with assistance."⁹

"Individuality means recognizing variability in residents' needs and preferences and having flexibility to organize services in response to such needs and preferences."

5. Developmental Disabilities Domiciliary Homes

Statutory Provision: Chapter 321, Section 321-15.9, Hawai'i Revised Statutes

Section 321-15.9, Hawai'i Revised Statutes, 1993 Replacement, provides the Department of Health with authority to license developmental disabilities domiciliary homes as stated,

- (a) The department of health is authorized to license developmental disabilities domiciliary homes for individuals with developmental disabilities or mental retardation who are unable to live independently and who require supervision or care, but do not require care by licensed nurses in a domiciliary setting.
- (b) For the purposes of this section, "developmental disabilities" shall be as defined under section 333E-2; and "mental retardation" shall be as defined under section 333F-1.
- (c) The director shall adopt rules regarding developmental disabilities domiciliary homes in accordance with chapter 91 which shall be designed to:
 - (1) Establish criteria for licensure of homes, including inspections, registration, fees, qualifications of operators and staff, and other factors necessary to ensure the safe and appropriate operation of each home;
 - (2) Protect the health, safety, and civil rights of persons residing in the homes:
 - (3) Provide for plans of care which include community integration and training of persons residing in the licensed homes;

⁹ Title 11, Department of Health, Chapter 90, Section 11-90-2, Hawai'i Administrative Rules

- (4) Provide for the licensure of homes of up to five persons who are developmentally disabled or mentally retarded, and who are not related to the home operator or facility staff;
- (5) Establish penalties for the failure to comply with any rule; and
- (6) Establish criteria for training of operators and staff of any facility licensed under this section.
- (d) Rules adopted under this section shall be enforced by the director.
- (e) The department shall maintain a registry of all facilities licensed under this section and a current inventory of vacancies to facilitate the placement of individuals in these facilities.
- (f) The rate of payment for residents in the developmental disabilities domiciliary homes shall be determined on the same basis as domiciliary care homes as provided under section 346-53.

Hawai'i Administrative Rules

Title 11, Department of Health, Chapter 89, Developmental Disabilities Domiciliary Homes

Chapter 89, Hawai'i Administrative Rules establishes minimum requirements for the certification and licensure of developmental disabilities domiciliary homes for adult individuals with developmental disabilities or mental retardation.

§11-89-1 Purpose

This chapter establishes minimum requirements for the certification and licensure of DD domiciliary homes for adult individuals with DD or mental retardation. These rules shall promote normalization, least restrictive intervention, community and social integration, personal development to fullest potential and protect the health, safety, and civil rights of residents in DD domiciliary homes. These rules shall not be construed as lowering the standards, ordinances, codes, and rules established by other government agencies. In the case of a conflict, the more stringent rules shall apply. ¹⁰

§11-89-2 Definitions

"Developmental disabilities domiciliary home means any facility licensed under this chapter to provide twenty-four supervision or care, excluding licensed nursing care, for a fee, to not more than five adults with mental retardation or developmental disabilities as defined under chapter 333F, HRS."

§11-89-3 Licensure

"(a) No person, or group of persons may operate a developmental disabilities domiciliary home unless it is licensed by the department." ¹²

§11-89-5 Certification

¹⁰ Title 11, Department of Health, Chapter 89, Section 11-89-1, Hawai'i Administrative Rules

¹¹ Title 11, Department of Health, Chapter 89, Section 11-89-2, Hawai'i Administrative Rules

¹² Title 11, Department of Health, Chapter 89, Section 11-89-3, Hawai'i Administrative Rules

- (a) The caregiver shall be capable of accepting, caring for, and training residents with developmental disabilities.
- (b) A certificate shall be issued to the caregiver when the caregiver has complete and passed the training requirements as stated in 11-89-7 and 11-89-8 of these rules.
- (c) Annual recertification shall be required in accordance with 11-89-8. 13

6. Intermediate Care Facility for Persons with Mental Retardation

Statutory Provision: Code of Federal Regulations 42 CFR 442, Standards for Payments for Skilled Nursing and Intermediate Care Facility Services

42 CFR 442 provides the standards for payments for skilled nursing and intermediate care facility services to Medicaid recipients.

Hawai'i Administrative Rules

Title 11, Department of Health, Chapter 99, Intermediate Care Facilities for the Mentally Retarded

§ 11-99-1 Purpose

This subchapter establishes minimum requirements for the protection of health, welfare, and safety of residents, personnel, and the public in small intermediate care facilities for the mentally retarded, and shall not be construed as lowering the standards, ordinances, or rules established by other government agencies. In all instances the more stringent rules shall apply.¹⁴

§ 11-99-2 Definitions

Small intermediate care facilities for the mentally retarded means an identifiable unit providing residence and care for fifteen or fewer mentally retarded individuals. Its primary purpose is the provisions of health, social, and rehabilitative services to the mentally retarded through an individually designed active treatment program for each resident. No person who is predominantly confined to bed shall be admitted as a resident.¹⁵

7. Residential Alternatives Community Care Program Foster Homes

Statutory Provision: Chapter 346, Section 346-14, Hawai'i Revised Statutes

¹³ Title 11, Department of Health, Chapter 89, Section 11-89-5, Hawai'i Administrative Rules

¹⁴ Title 11, Department of Health, Chapter 99, Section 11-89-1, Hawai'i Administrative Rules

¹⁵ Title 11, Department of Health, Chapter 99, Section 11-89-2, Hawai'i Administrative Rules

The Residential Alternatives Community Care Program is a Medicaid waiver program for adults who have significant functional/medical needs and choose to live in alternative community-based home because they can no longer live in their own home.

Hawai'i Administrative Rules

Title 17, Department of Human Services, Subtitle 9, Community Long-Term Care Programs, Chapter 1440, Home and Community-Based Services for Elderly Foster Family Community Care Program

Chapter 1440 establishes the provisions to provide home and community-based services, which assist elderly persons with chronic illnesses and disabilities to remain in a family home as an alternative to institutionalization.

8. Semi-Independent

Statutory Provision: None

Hawai'i Administrative Rules: None

Individuals may live in agency-operated apartments that are not licensed, but regulated by United States Department of Housing and Urban Development. Minimal supervision is provided on-site by agency staff.

According to Stancliffe and Whaite, 1997; Van Dam, and Cameron-McGill, 1995, the definition for semi-independent living "is for individuals with the mildest disabilities who can succeed with low levels of paid staff support (10-20 hours a week)."

9. Therapeutic Living Program

Statutory Provision: Chapter 321, Section 321-11, Hawai'i Revised Statutes

Hawai'i Administrative Rules

Title-11, Department of Health, Chapter 92, Therapeutic Living Programs

§ 11-92-1 Purpose and Scope

The purpose of this chapter is to establish minimum standards of accreditation, certification, and licensure for the protection of health, welfare, and safety of residents, personnel, and the public in therapeutic living programs serving populations receiving child and adolescent mental health, substance abuse, and developmental disabilities services. ¹⁶

Hawai'i Administrative Rules

Title-11, Department of Health, Chapter 92, Therapeutic Living Programs, Subchapter 6, Specific Terms for Certification for Therapeutic Living Programs for Persons with Developmental Disabilities/Mental Retardation.

¹⁶ Title 11, Department of Health, Chapter 92, Section 11-92-2, Hawai'i Administrative Rules

§11-92-74 Standards for therapeutic living programs for persons with developmental disabilities/mental retardation

- (a) General provisions. In addition to the requirements set forth in subchapters 1, 2, and 3 the requirements in this part shall apply to short term and long term residential services for the developmentally disabled/mentally retarded.
 - (b) Therapeutic living programs serve persons with developmental disabilities/mental retardation for which out of home placement is required, and who are able to function in a community-based home-like setting.
 - (c) Therapeutic living programs serve persons with DD/MR who reside in a home with a full-time resident manager and are receiving PA and/or HABS services.
 - (d) Therapeutic living programs may access therapy and special education services through linkage with other community-based resources.
 - (e) Therapeutic living programs may provide crisis shelter or respite services.
 - (f) The program shall have policies and procedures which shall contain, at minimum, the following:
 - (1) The formulation of discharge plans; and
 - (2) Six months of on-going monitoring of the status of discharged residents. 17

"Chapter 92 is being promulgated; however, during this process TLPs are being licensed via Chapter 98 STF regulations with waivers, under Memorandum of Agreement with DD Division." ¹⁸

10. Special Treatment Facilities

Statutory Provision: Chapter 321, Section 321-11, Hawai'i Revised Statutes

Hawai'i Administrative Rules Title 11, Department of Health, Chapter 98, Special Treatment Facility

§ 11-98-2 Definitions

"Special treatment facilities means a facility which provides a therapeutic residential program for care, diagnoses, treatment or rehabilitation services for socially or emotionally distressed persons, mentally ill persons, persons suffering from substance abuse, and developmentally disabled persons" 19

¹⁷ Title 11, Department of Health, Chapter 92, Subchapter 6, Section 11-92-74, Hawai'i Administrative Rules

¹⁸ Department of Health, Developmental Disabilities Division Information Sheet, Summary of Licensed and Certified Residential Settings

¹⁹ Title 11, Department of Health, Chapter 98, Section 11-98-2, Hawai'i Administrative Rules

"Program means the evaluation, counseling, prevention, habilitation, rehabilitation or services directed toward achieving social, emotional, mental and physical restoration of the residents." 19

11. Family

Statutory Provision: None

Hawai'i Administrative Rules: None

Individual resides in his/her family's home with no requirements or regulations for licensure.

12. Independent Living

Statutory Provision: None

Hawai'i Administrative Rules: None

Independent is not contingent on something else from control or influence.

Clients may live independently:

- a. in their parents home
- b. in an apartment which they are renting
- c. group living situation
- 1. licensed under the City and County for 5 unrelated individuals
- 2. rental agreement in place
- 3. resident manager available to check on the home, and not provide care or supervision

In an independent setting, clients should be able to:

- a. prepare their own meals, manage their own laundry, housekeeping chores
- b. able to access medical services
- c. able to manage own medications
- d. has basic skills to meet his or her own personal needs (ADLs)
- e. may require assistance for arrangement for transportation, assistance for coordination of services required and/or seeking, assistance in shopping, help with meal planning, arrangement for outings.²⁰

²⁰ Department of Health, Developmental Disabilities Division Information Sheet, Summary of Licensed and Certified Residential Settings

IV. INVENTORY OF RESIDENTIAL OPTIONS

The Department of Health, Developmental Disabilities Division licenses and/or certifies two types of residential settings:

- 1. Developmental Disabilities Domiciliary Homes; and
- 2. Adult Foster Homes for individuals with developmental disabilities.

Both types of homes must meet:

- a. City and County building codes;
- b. Criminal History Checks; and
- c. Financial viability.²¹

Homes are initially licensed/certified and inspected on an annual basis by Department of Health, Office of Health Care Assurance. Office of Health Care Assurance has the responsibility through the State Licensing Section to promulgate State licensing rules and regulations which set forth standards of care and safety as required by the Hawai'i Revised Statutes to ensure quality of care for residents in the following community-based settings: Adult Residential Care Homes, Expanded Adult Residential Care Homes, Special Treatment Facilities, Therapeutic Living Programs, Domiciliary Homes, and Assisted Living Facilities.

Payments for the above residential settings are paid through State Supplemental Payment (combination of Federal and State dollars) as "individuals living in domiciliary care". Payment of \$1,085.90* per month per individual residing in the home, of which \$30.00 is the resident's monthly allowance.

Additional services needed by the individual may be obtained through the Medicaid Home and Community-Based Services Waiver program.

Currently, there are 26 individuals statewide who are living in 10 homes that are not licensed.²²

* Rate effective 1/04-12/04 (Department of Human Services, Standard of Assistance for Financial and Food Stamp Programs, 11/19/03)

²¹ Department of Health, Developmental Disabilities Division Information Sheet, Licensed/Certified Residential Settings for Person with Developmental Disabilities, 9/08/03.

²² Minutes from Department of Health, State Council on Developmental Disabilities Residential Settings Task Force Meeting held on July 22, 2004.

Table 1 Settings in Which People With Developmental Disabilities Live by County
October 2004

Type	Oʻahu	Hawai'i	Mauʻi	Kauaʻi	Total ¹
Adult Foster	418	12	24	16	463
Alone	54	32	8	13	104
Assisted Living	7	-	-	-	7
Care Home (1-5)	152	12	1	9	171
Care Home (+6)	5	-	-	3	8
Child Foster	20	11	3	1	34
DD Dom	129	3	7	-	135
Ext Care Home	62	1	4	1	67
Hospital	4	1	1	-	6
ICF/MR-C ²	2				2
Institution	5	-	-	-	5
NF	6	-	1	3	10
Other ³	46	5	4	-	52
Family	1405	310	165	133	1997
With Other ⁴	33	6	4	4	47
No Entry	58	5	8	8	78
Total	2406	392	228	188	3115

Source: Department of Health, Developmental Disabilities Division

The residential setting most used by individuals with developmental disabilities are family (64 percent), adult foster and developmental disabilities domiciliary homes (19 percent), care homes (8 percent), and independent living (3 percent).

¹ Total Figures are duplicated counts. Total of 3115 is an unduplicated count.

² Persons are receiving additional services from Developmental Disabilities Division.

³ The category of "Other" includes other facilities.

⁴ "With Other" includes individuals living with people other than his/her family.

Table 2 List of Developmental Disabilities Domiciliary Homes in Hawai'i November 8, 2004

	Oʻahu	Hawai'i	Mauʻi	Kauaʻi	Total
Agency	10- (Arc)	1- (Kona Krafts)	1- (Arc of Mau'i)	0	17
Operated	2- (ORI)				
	3- (RCH)				
Mom and Pop	11	0	1	0	12
Total	26	1	2	0	29

Source: Department of Health, Developmental Disabilities Division

Table 2 represents the number of developmental disabilities domiciliary homes operated by private provider agencies or mom and pop (family). There are three private providers (The Arc in Hawaii, ORI-Opportunities for the Retarded, and RCH-Responsive Caregivers of Hawai'i) that operate developmental disabilities domiciliary homes. Agency-operated homes comprise 59% (17) of the developmental disabilities domiciliary homes and mom and pops 41% (12) of those homes.

Table 3 Office Of Health Care Assurance Licensing Section Data October 21, 2004

Adult Residential Care Home (ARCH) includes Type I, Type II and Expanded Care

Total number in State = 506

Total resident capacity = 2638

Breakdown by Island:

Number of	Capacity	
Mauʻi	13	62
Hawai'i	49	215
Kauaʻi	15	70
Moloka'i	4	31
Oʻahu	<u>425</u>	<u>2260</u>
TOTAL	506	2638

Current/pending ARCH applications = 30

Special Treatment Facilities (STF)

Total Number in State = 30

Total Resident Capacity = 685

Current/pending STF applications = 4

Therapeutic Living Programs (TLP)

Total Number in State = 14

Total Resident Capacity = 99

Current/pending TLP applications – 4

Developmental Disabilities Domiciliary Homes (DDDH)

Total Number in State = 36

Total Resident Capacity = 157

Current/pending DDDH applications = 2

Assisted Living Facilities (ALF)

Total Number in State = 9

Total Resident Capacity = 1271

Current/pending ALF applications = 0

Source: Department of Health, Office of Health Care Assurance

Table 3 provides information on the types of residential setting, number of units, resident capacity, and pending applications.

V. ADDRESS INDIVIDUAL CHOICE AND SELF-DETERMINATION IN INCREASING RESIDENTIAL OPTIONS, INCLUDING RESIDENCY IN UNLICENSED HOMES FOR INDIVIDUALS WITH DEVELOPEMENTAL DISABILITIES SUCH AS ADULT RESIDENTIAL CARE HOMES, ADULT FOSTER HOMES, AND DEVELOPMENTAL DISABILITIES DOMICILIARY CARE HOMES OR THOSE IN THE PROCESS OF BEING LICENSED

As the direction of providing services and supports moves to more consumer-control and consumer-directed, issues surrounding licensing have surfaced. The State is challenged in allowing individual choice and self-direction while meeting statutory, administrative and regulatory requirements.

Issues

The Task Force sought to address and balance the fine line between choice and control with health, safety, and welfare. Health, safety, and welfare seem to be the three core factors guiding statutes and administrative rules. The Task Force identified significant issues that surround and impact on individual choice and self-determination. Those issues included, but were not limited to, choice of residential settings; rate of payment; licensing and regulations; factors in assuring health, safety, and welfare; liability; and dignity of risk.

Those issues were categorized according to the following five areas:

- A. General
- B. Licensure/Regulations
- C. Health, Safety and Welfare
- D. Hawai'i Revised Statutes and Administrative Rules
- E. Liability

The Task Force identified numerous issues and recognized the complexity of those issues. As a result, there was agreement that further review and analysis was needed in order to fully address the scope of this section. Consequently, the Task Force will continue its work in addressing individual choice and self-determination in increasing residential options. Detailed information under this section will be included in a follow up (Phase 2) report to the 2006 Legislature.

VI. STATUTES, ADMINISTRATIVE RULES, POLICIES, AND DIRECTIVES TO REVISE TO ALLOW HOMES THAT ARE NOT LICENSED BUT DETERMINED TO PROVIDE SAFE AND HEALTHY ENVIRONMENTS AS A RESIDENTIAL OPTION

Numerous questions were identified as overarching and cut across all aspects of residential settings with current statutes, administrative rules and regulations.

- 1) What are the issues of health, safety and welfare?
- 2) What factors guarantee health, safety and welfare?
- 3) How can an individual's health and safety be assured in any given setting?
- 4) What is the minimum accepted standards to assure health, safety and welfare?
- 5) How do we balance individual choices and assure health, safety and welfare?
- 6) What is an ideal number of individuals to live in a home before the home must be licensed?
- 7) What needs to be done to allow individuals to remain in their current living arrangement?
- 8) How much risk is allowed for an individual?
- 9) Who determines what needs to be licensed?

Present statutory provisions, administrative rules, policies and directives for adult residential care homes, adult foster homes, and developmental disabilities domiciliary homes were reviewed to determine if they address and support individual choice and self-determination, and assure civil rights, health, and safety.

The following is a review and description of the statutes, administrative rules, policies and directives that govern adult residential care homes, adult foster homes and developmental disabilities domiciliary homes for individuals with developmental disabilities. The description of statutes, administrative rules, policies, and directives may not contain its entire provision. Only pertinent sections that directly relate to the above residential settings were included in this section.

1. Code of Federal Regulations, Subpart G, Home and Community-Based Services: Waiver Requirements

§ 441.302 State Assurances

Unless the Medicaid agency provides the following satisfactory assurances to CMS, CMS will not grant a waiver under this subpart and may terminate a waiver already granted:

- (a) *Health and Welfare* Assurance that necessary safeguards have been taken to protect the health and welfare of the recipients of the services. Those safeguards must include-
- (1) Adequate standards for all types of providers that provide services under the waiver:

- (2) Assurance that the standards of any State licensure or certification requirements are met for services or for individuals furnishing services that are provided under the waiver; and
- (3) Assurance that all facilities covered by section 1616(e) of the Act, in which home and community-based services will be provided, are in compliance with applicable State standards that meet the requirements of 45 CFR Part 1397 for board and care facilities.²³

2. American with Disabilities Act Title II, Public Services, Subtitle A: Prohibition Against Discrimination and Other Generally Applicable Provisions

According to the American with Disabilities Act of 1990 Sec. 202, discrimination is defined as, "Subject to the provisions of this title, no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity."

3. United States Supreme Court decision in Olmstead v. L.C., 119 S. Ct. 2176 (1999)

What did the Court say about Integration?

- A. Institutional placement of persons who can handle and benefit from community settings perpetuate unwanted assumptions that persons so isolated are incapable or unworthy of participating in community life.
- B. Confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.
- C. Olmstead affirmed the American with Disabilities Act integration mandate.
 - The American with Disabilities Act's anti-discrimination provisions prohibit state from placing a person in an inappropriate institutional placement.
 - Requires states to make reasonable modifications to its existing programs to avoid inappropriate institutionalization.
 - To accommodate community placement, a state needs to make reasonable accommodations, but does not need to make fundamental alterations on the services or programs.

4. Chapter 333F, Hawai'i Revised Statutes, 2003 Cumulative Supplement, Services for Persons with Developmental Disabilities or Mental Retardation

Section 333F-1: Definitions

²³ Code of Federal Regulations, Subpart G, Home and Community-Based Services: Waiver Requirements, Section 441.302 State assurances

Individualized Service Plan: means the written plan required by section 333F-6 that is developed by the individual with the input of family, friends, and other persons identified by the individual as being important to the planning process. The plan shall be a written description of what is important to the person, how any issue of health or safety shall be addressed, and what needs to happen to support the person in the person's desired life.²⁴

Section 333F-2: Developmental disabilities system

"(a)....The department shall administer or may provide available supports and services based on a client-centered plan, which resulted from client choices and decision-making that allowed and respected client self-determination..."²⁵

Section 333F-7: Provision of services

The department shall:

- (1) Assist the individual to develop, with the help of family and friends, if necessary, an individualized service plan;
- (2) Identify the amount of dollars available to the individual to effectuate the individualized service plan; and
- (3) Allow consumers to direct the expenditures of the identified funds. ²⁶

Section 333F-8: Rights of persons with developmental disabilities or mental retardation

- (a) Persons with developmental disabilities shall have the following rights:
- (1) To receive the least restrictive, individually appropriate services, including a program of activities outside the residence in accordance with the person's individualized service plan;
- (2) To reside in the least restrictive, individually appropriate residential alternative located as close as possible to the person's home community within the State;
- (3) To the extent it is individually appropriate as decided after due consideration afforded the preferences of the person with developmental disabilities or mental retardation, to:
- (A) Interact with persons without disabilities in a nontreatment, nonservice-oriented setting;
- (B) Live with, or in close proximity to, persons without disabilities; and
- (C) Live in a setting which closely approximates those conditions available to persons without disabilities of the same age;
- (4) To reasonable access to review medical, service, and treatment files and to be informed of diagnoses;
- (5) To develop a plan with the input of family and friends that identifies the supports needed to accomplish the plan rather than purchase a program;

²⁴ Chapter 333F, Section 333F-1, Hawai'i Revised Statutes, 2003 Cumulative Supplement

²⁵ Chapter 333F, Section 333F-2, Hawai'i Revised Statutes, 2003 Cumulative Supplement ²⁶ Chapter 333F, Section 333F-7, Hawai'i Revised Statutes, 2003 Cumulative Supplement

- (6) To control, with the help of family and friends as necessary, an identified amount of dollars to accomplish the plan;
- (7) To direct the provision of resources, both paid and unpaid, that will assist an individual with a disability to live a life in the community rich in community association and contribution;
- (8) To a valued role in the community through employment, participation in community activities, volunteering, including being accountable for spending public dollars in ways that are life enhancing; and
- (9) To privacy and confidentiality, to the extent possible, in connection with services provided to the person.
- (b) Rights listed in this chapter shall not be construed to replace or limit any other rights, benefits, or privileges, including other statutory and regulatory due process rights and protections, to which a person with a developmental disability or mental retardation may be entitled.
- (c) The enumeration or granting of these rights does not guarantee the provision of services.²⁷

5. Chapter 321, Department of Health, Hawai'i Revised Statutes, 2003 Cumulative Supplement

Section 321-11: Subjects of health rules, generally

The department pursuant to chapter 91 may adopt rules that it deems necessary for the public health and safety respecting:

- ...(10) Hospitals, freestanding surgical outpatient facilities, skilled nursing facilities, intermediate care facilities, adult residential care homes, adult foster homes, assisted living facilities, special treatment facilities and programs, home health agencies, hospices, freestanding birthing facilities, adult day health centers, independent group residences, and therapeutic living programs, but excluding youth shelter facilities unless clinical treatment of mental, emotional, or physical disease or handicap is a part of the routine program or constitutes the main purpose of the facility, as defined in Section 346-16 under "child care institution". For the purpose of this paragraph, "adult foster home" has the same meaning as provided in Section 321-11.2;
- (11) Hotels, rooming houses, lodging houses, apartment houses, tenements, and residences for persons with developmental disabilities including, but not limited to those built under federal funding...

The department may require any certificates, permits, or licenses that it may deem necessary to adequately regulate the conditions or businesses referred to in this section.²⁸

²⁸ Chapter 321, Section 321-11, Hawai'i Revised Statutes, 2003 Cumulative Supplement

²⁷ Chapter 333F, Section 333F-8, Hawai'i Revised Statutes, 2003 Cumulative Supplement

- Section 321-11.2: Adult Foster Homes
 Refer to Section III. Residential Options Available
- Section 321-15.6: Adult residential care homes; licensing. Refer to Section III. Residential Options Available
- Section 321-15.62: Expanded adult residential care homes; licensing. Refer to Section III. Residential Options Available
- Section 321-15.9: Developmental disabilities domiciliary homes. Refer to Section III. Residential Options Available

6. Hawai'i Administrative Rules

Title 11, Department of Health, Chapter 89, Developmental Disabilities Domiciliary Homes
Refer to Section III. Residential Options Available

7. Hawai'i Administrative Rules

Title 11, Department of Health, Chapter 148, Certification of Adult Foster Homes
Refer to Section III. Residential Options Available

8. Hawai'i Administrative Rules

Title 11, Department of Health, Chapter 100, Adult Residential Care Homes
Refer to Section III. Residential Options Available

VII. STATUTES, ADMINISTRATIVE RULES, POLICIES, AND DIRECTIVES THAT NEED TO BE REVISED TO REFLECT INDIVIDUAL CHOICE AND ASSURE CIVIL RIGHTS, HEALTH AND SAFETY

The Task Force is in the process of completing its review and analysis of this section. Information and recommendations will be included in the follow up report (Phase 2) to be submitted to the 2006 Legislature.

The following statutes and administrative rules were identified to be reviewed to determine what revisions are needed to support and reflect individual choice and assure civil rights, health and safety.

1. Adult Foster Homes

Chapter 321, Section 321-11.2, Hawai'i Revised Statutes, Title 11, Department of Health, Chapter 148, Hawai'i Administrative Rules,

2. Adult Residential Care Homes

Chapter 321-15.1, Hawai'i Revised Statutes Title 11, Department of Health, Chapter 100, Hawai'i Administrative Rules

Licensing

Chapter 321, Section 321-15.6, Hawai'i Revised Statutes

Expanded Admissions

Chapter 321, Section 321-15.61, Hawai'i Revised Statutes

Expanded Licensing

Chapter 321, Section 321-15.62, Hawai'i Revised Statutes

3. Developmental Disabilities Domiciliary Homes

Chapter 321, Section 321-15.9, Hawai'i Revised Statutes, Title 11, Department of Health, Chapter 89, Hawai'i Administrative Rules

4. Services for Persons with Developmental Disabilities or Mental Retardation

Chapter 333F, Hawai'i Revised Statutes

VIII. COORDINATE ACTVITIES WITH THE OLMSTEAD TASK FORCE TO PREVENT DUPLICATION OF WORK

The Olmstead Task Force completed its Implementation Plan and will be submitted to the Governor. The Implementation Plan includes Senate Concurrent Resolution 79 Senate Draft 1 House Draft 1 as an action item under "Objective 3b2: Review state regulations so that people with disabilities, their families and caregivers can decide how their individual benefits will be used for home services of their choice" and "Objective 3b3: Identify policies that create disincentives to independent community living and consumer choice by establishing a mechanism for people with disabilities, their families and caregivers to provide feedback." ²⁹

The report will be shared with the Olmstead Task Force, and efforts will be made to coordinate the implementation of the Residential Settings Task Force's recommendations with the activities of the Olmstead Implementation Plan.

²⁹ Recommended Olmstead Implementation Plan, Appendix B, November 8, 2004

IX. CONCLUSION

The Task Force acknowledges that Sections V., VI., and VII. do not include detailed information to formulate any specific recommendations to address the intent and scope of Senate Concurrent Resolution 79 Senate Draft 1 House Draft 1. There were numerous discussions within the Task Force about the issues and possible solutions. However, due to the complexities of the issues and the scope of reviewing and analyzing pertinent statutes, administrative rules, policies, and directives, the Task Force believes it needs additional time to fully accomplish the intent and goal of Senate Concurrent Resolution 79 Senate Draft 1 House Draft 1.

The State is challenged with the current housing crisis for people with and without disabilities, compounded by rising costs of living, aging parent caregivers, and available and affordable housing. Increasing residential options and supporting individuals with developmental disabilities in their choice of residential settings is a very important and vital endeavor on both moral and legal grounds for the State to achieve, it is an endeavor that cannot be ignored but one whose time has come.

X. Appendices

Appendix A

THE SENATE S.C.R. NO. 79

TWENTY-SECOND LEGISLATURE, 2004

S.D. 1

STATE OF HAWAII H.D. 1

SENATE CONCURRENT RESOLUTION

REQUESTING THE HAWAII STATE COUNCIL ON DEVELOPMENTAL DISABILITIES TO CONVENE A TASK FORCE TO IDENTIFY ISSUES AND SOLUTIONS REGARDING INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES AND THEIR CHOICE OF RESIDENTIAL SETTING.

WHEREAS, sixty-two percent of individuals with developmental disabilities live with their family; and

WHEREAS, at least thirty percent of individuals with developmental disabilities who receive services from the Department of Health (DOH), Developmental Disabilities Division (DDD), live in licensed or certified residential settings; and

WHEREAS, DDD serves approximately 3,300 individuals with developmental disabilities, over 1,800 of which are served under the Title XIX Medicaid Home and Community-Based Services Waiver for individuals with developmental disabilities or mental retardation (DD/MR); and

WHEREAS, DDD has established a Waiver Policy Advisory Committee (PAC) to provide input and recommendations on the DD/MR waiver; and

WHEREAS, the State Council on Developmental Disabilities (Council) is a member of PAC; and

WHEREAS, at the recommendation of PAC and direction of the Council's Executive Committee, the Council initiated meetings with DDD and DOH's Office of Health Care Assurance, self-advocates, family members, service providers, and other advocates to review current licensing requirements for various residential settings, including adult residential care homes, adult foster care homes, and developmental disabilities

domiciliary care homes, and provisions in current statutes, administrative rules, policies, and directives which conflict with the principles of self-determination, the Olmstead decision, and Title II of the Americans with Disabilities Act; and

WHEREAS, Chapter 333F, Hawaii Revised Statutes, incorporates the principles of self-determination by giving individuals with developmental disabilities the authority to direct their own budget and service plan; and

WHEREAS, as individuals exercise their right to make choices and direct their own budget and service plan, a variety of residential options must be available; and

WHEREAS, the United States Supreme Court decision in Olmstead v. L.C., 119 S. Ct. 2176 (1999) (Olmstead decision) provides an important legal framework to enable individuals with disabilities to live in the most integrated setting appropriate to their needs; and

WHEREAS, one of the goals of Hawaii's Olmstead Plan states, "Each individual will be supported in finding an appropriate, affordable and accessible home of their choice in a timely and efficient manner;" and

WHEREAS, the number of individuals with challenging behaviors and dual diagnosis of developmental disabilities and mental illness who need additional support to live in the community is increasing; and

WHEREAS, inadequate funding in the service system creates a low supply of services, resulting in waiting lists and individuals choosing institutional care; and

WHEREAS, current Social Security income does not meet minimum wage requirements; and

WHEREAS, a recent local newspaper article reported that, "Hawaii is among the top eight states for growth in the over sixty-four population"; and

WHEREAS, there is an increase in the number of aging caregivers, resulting in a decrease in the option of living at home, thus decreasing residential options; now, therefore,

BE IT RESOLVED by the Senate of the Twenty-second Legislature of the State of Hawaii, Regular Session of 2004, the House of Representatives concurring, that the Council is requested to convene a Task Force to identify issues and solutions regarding individuals with developmental disabilities and their choice of residential setting; and

BE IT FURTHER RESOLVED that in identifying issues and solutions, the Task Force:

- (1) Identify residential options available;
- (2) Address individual choice and self-determination in increasing residential options, including residency in unlicensed homes for individuals with DD, such as adult residential care homes, adult foster homes, and developmental disabilities domiciliary care homes or those in the process of being licensed;
- (3) Identify statutes, administrative rules, policies, and directives to revise to allow homes that are unlicensed, but determined to provide safe and healthy environments, as a residential option;
- (4) Identify statutes, administrative rules, policies, and directives that need to be revised to reflect individual choice and assure civil rights, health, and safety; and
- (5) Coordinate its activities with the Olmstead Task Force to prevent duplication of work; and

BE IT FURTHER RESOLVED that the Task Force include representatives from the following agencies, organizations, or affiliations:

- (1) Individuals with developmental disabilities;
- (2) Family members of individuals with developmental disabilities;
- (3) DOH, Developmental Disabilities Division;
- (4) DOH, Office of Health Care Assurance;
- (5) DOH, Adult Mental Health Division;
- (6) DOH, State Council on Developmental Disabilities;

- (7) Department of Human Services, Social Services Division;
- (8) Hawaii Disability Rights Center;
- (9) Office of the Public Guardian;
- (10) Residential services providers such as operators of adult residential care homes, developmental disabilities domiciliary care homes, and adult foster homes; and
- (11) Support services providers; and

BE IT FURTHER RESOLVED that the Task Force is requested to submit its findings and recommendations, including any proposed legislation, to the Legislature no later than twenty days prior to the convening of the Regular Session of 2005; and

BE IT FURTHER RESOLVED that the Department of Health is requested to not take any action which would result in the relocation of any individuals with developmental disabilities without their consent from a home in which they reside merely because of the failure of the home to be licensed; and

BE IT FURTHER RESOLVED that certified copies of this Concurrent Resolution be transmitted to the Chair and Executive Administrator of the Hawaii State Council on Developmental Disabilities, Director of Health, Director of Human Services, President of the Hawaii Disability Rights Center, and Director of the Office of the Public Guardian.

Report Title:

Developmental Disabilities Task Force

Appendix B

List of Residential Settings Task Force Members

The Task Force was to include representatives from the following agencies, organizations, or affiliations:

- 1. Waynette Cabral, State Council on Developmental Disabilities
- 2. Espe Cadavona, Support Services Provider
- 3. Ellen Ching, Support Services Provider
- 4. Louis Erteschik, Hawaii Disability Rights Center
- 5. Maria Etrata, Operators of adult residential care homes and adult foster homes
- 6. Dave Fray, DOH, Developmental Disabilities Division
- 7. Liz Ann Ihu, Family member of an individual with developmental disabilities
- 8. Patty Johnson, DHS, Support Services Division
- 9. Dr. Jane Kadohiro, DOH, Office of Health Care Assurance
- 10. Steve Kula, Residential Services Provider (Developmental Disabilities Domiciliary Homes)
- 11. Cathy Lowder, Office of the Public Guardian
- 12. Haaheo Mansfield, Family member of an individual with developmental disabilities
- 13. Dianne Okumura, DOH, Office of Health Care Assurance
- 14. Deborah Rivers, Individual with developmental disabilities
- 15. Millie Rogers, Individual with developmental disabilities
- 16. Dr. Linda Rosen, DOH, Developmental Disabilities Division
- 17. Rose Shin, State Council on Developmental Disabilities
- 18. Michael Tamanaha, DOH, Developmental Disabilities Division
- 19. Garrett Toguchi, Family member of an individual with developmental disabilities
- 20. Barbara Yoshioka, DOH, Office of Health Care Assurance
- 21. Kathy Yoshitomi, DOH, Adult Mental Health Division

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Summary of Residential Settings

Type of Residence	HAR/HRS	License / Certification	Funding		ent Amount Ionthly	# of unit			Capacity					# pending applicants	Max # people per unit		
						Oahu	Hawaii	Maui	Kauai	Total	Oahu	Hawaii	Maui	Kauai	Total		
Adult Foster Home	Chap. 148	DOH/DDD	Social Security Income (SSI) benefits	Fed	\$564.00												
ridait i obtoi i iomo	HRS 321-11	5017555	for Medicaid eligible and State	State	\$521.90												2
			Supplemental Payment (SSP)	Total	\$1,085.90												
Adult Residential Care Home (ARCH)	Chap 100 (100.1 pending)	DOH / OHCA	SSI and SSP benefits for Medicaid eligible & private pay from \$2,000- \$6,000	Fed	\$564.00												Type I: 5
	HRS 321-11		Same as above	State	\$521.90	425	49	17	15	506	2260	215	93	70	2,638	30	Type II: 6 or more
Expanded Care		DOH / OHCA / DHS contract	Same as above	Total	\$1,085.90												Type I: 2 Type II: 20% of capacity
Assisted Living Facility (ALF)	Chap. 90	DOH / OHCA	\$2,000 to \$4,000 w/ add'l costs at an ala carte rate depending on types of services provided			6	1	1	. 1	. 9	807	220	144	100	1,271	0	n/a
Developmental Disabilities	Chap. 89	DOLL/OLIOA/	SSI and SSP	Fed	\$564.00												
Domiciliary Homes	HRS 321-11	DOH / OHCA DDD		State	\$521.90	28	1	2	2	31	125	5 5	8		138	2	5
(DDDom)				Total	\$1,085.90												
Intermediate Care Facilities for persons with	Chap. 99 & Fed. Reg.	DOH / OHCA	Medicaid rates	DHS + CMS	\$8,070.15	17		4		21	79		24		103	0	Small: 8 or less
mental retardation (ICF/MR)	42CFR, 442, 483.400 - 483.480																Large: 9 or more
Residential Alternatives	Modicaid Waiver regulations			Fed	\$564.00												
Community Care Program (RACC)	Medicaid Waiver regulations & requirements	DHS	SSI and SSP	State Total	\$521.90 \$1,085.90	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
Semi- Independent			Rent is maximum 30% of income, and Section 8 if available			48				48	48				48		1
Therapeutic Living	Chap. 92 Chapter 98, HRS	DOH / OHCA	SSI benefits w/ additional wrap around services	Fed	\$564.00	0	2	2		1.4	52	12	23	12	99	4	NA
Program (TLP)		DOH / OHCA				0		2		14	32	12	23	12	99	4	INA
Special Treatment Facilities (STF)	CH.98, HRS 321.11, STF regs. w/ waivers under Memorandum of Agreement w/ DDD	DOH /OHCA				30	2	4		36	577	37	75		689	4	
Family			SSI benefits w/ additional wrap around services	Fed	\$564.00												
Independent			SSI and Private pay or Section 8 allowable	Fed	\$564.00					NA					NA		
		•			TOTALS	562	55	30	18	665	3948	489	367	182	4986	40	8

Summary of Residential Settings

Current Residents			dents		Persons Eligible	Services	Comments
Oahu	Hawaii Maui Kauai Total			Total			
418	12	Waui 24	16	470	DD & unrelated to family	24 hr. care & training. Emphasis on creating home environment	
152	12	1	9		Unrelated to family, does not need ICF & requires minimal assist w/ ADL[1], does not need skilled or professional personnel on long term basis.	24 hr. living accommodations, minimal assist w/ ADL	Activities of Daily Living including personal care, shelter, protection, supervision, assistance, guidance or training, planned activities, food services, recognition of & provision for changes in health status, & arrangement for & transportation to medical & dental offices.
5			3	8	Persons requiring an ↑ level of care may remain in an ARCH until transfer if the operator is deemed capable by the DOH		
62	1	4	1	68	Individuals @ nursing facility (NF) level of care in an established ARCH.	24hr. living accommodations	
7				7		Meals, 24 hour staff available, individualized services to achieve greatest capacity to live independently	Facility shall be designed to maximized independence & self-esteem of limited mobility persons who feel they are no longer able to live on their own
129	3	7		139	MR or DD per HRS 333F	24 hr. care & supervision excluding licensed nursing care	
				0	DD, unrelated to caregiver, resides in a dom home for a fee, unable to live independently, requires supervision, care & training, & does not require care by a licensed nurse, excludes individuals predominantly confined to a bed	Individualized active treatment prg.; providing health, social & rehabilitative services	
NA	NA	NA	NA	NA	Individuals at the Skilled Nursing Level or ICF level of care that meet certain financial eligibility standards and can be cared for safely in a foster family home.	Adult Foster Care and case management in a community setting that meets their medical, ADL and IADL needs.	
48				48			
				0	Individuals or families who do not need the structure of a STF & are transitioning from a more restrictive setting to independent living	Mental health or substance abuse services	
				0			
1405	310	165	133	2013			
87	38	12	17	154			
2313	376	213	179	3081		I	1